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USA's experience with sudden unexpected infant death and sudden death in the young case registries

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We read with great interest, 'A national registry for sudden unexpected deaths of infants and children in England: why do we need one and do families want one?'¹ In the USA's experience, getting feedback from parents and other stakeholders was an important first step to implementing sudden unexpected infant death (SUID) and sudden death in the young (SDY) registries.²³ Starting a registry in England is key to better understanding the causes of these tragic deaths so they can be prevented.

Although mortality data derived from death certificates are often used to monitor and track trends in sudden deaths among infants and children, death certificate surveillance has limited ability to capture details of the events and circumstances surrounding these deaths.² In addition, for infants, US death certificate surveillance is affected by variations in cause-of-death reporting, making it necessary to combine underlying cause-of-death codes for SIDS, other ill-defined and unspecified causes of mortality, and accidental suffocation and strangulation in bed into a combined category, SUID.⁴ Although the SUID category facilitates more consistent tracking of mortality trends, the combined category does not enable researchers to distinguish between explained (eg, accidental suffocation) and unexplained causes (eg, unexplained sudden deaths).⁴ To address these shortcomings in surveillance, the US Centers for Disease Control and Prevention (CDC) and the US National Institutes of Health (NIH) established SUID (infants <365 days)² and SDY (children 20 years) registries.³ The SUID and SDY case registries supplement death certificate surveillance in multiple sites across the USA, by providing detailed information about death circumstances and autopsy findings, as well as biospecimens for SDY research only.

In 2009, the CDC launched the SUID case registry as part of a cooperative agreement between CDC and five states.² CDC's involvement with SUID case registry awardees includes collaboration and joint participation on implementing parts of the programme, sharing technical and subject matter expertise, monitoring of activities and training, as well

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as providing collaborative learning opportunities. In 2014, CDC and NIH launched the SDY case registry,³ using protocols and methods from the SUID case registry as templates.²⁵ Collaborative efforts between CDC and NIH allowed support for additional cooperative grant awardees; standardisation of autopsies; multijurisdictional surveillance of sudden deaths up to age 20 and extensive postmortem clinical review, biospecimen collection and genetic testing. Currently, the SUID and SDY case registries include 22 awardees, encompassing 17 states and 5 jurisdictions (figure 1). All awardees are conducting SUID surveillance and a subset participate in SDY surveillance.

The US registries are built on the National Center for Fatality Review and Prevention's Child Death Review programme infrastructure.⁶ The Child Death Review programme benefits from teams of multidisciplinary professionals (eg, those responsible for investigating these deaths or protecting child health and safety) who come together and review sudden unexpected deaths among infants and children. Teams review and discuss findings from death scene investigations and autopsies, including but not limited to investigation reports, doll re-enactments, scene photos, interviews with parents and other witnesses, toxicology findings, emergency services reports and law enforcement records. The Child Death Review programme, in existence since 2002, had review protocols, team structures and a web-based case reporting system that most states used before CDC and NIH implemented the SUID and SDY case registries.

To address concerns about variability in cause-of-death reporting found in death certificate data, the CDC and NIH registries apply standardised classification and decision-making algorithms.³⁵ The SUID case registry classification system groups deaths into categories based on thoroughness of case investigation, factors contributing to death, certainty that factors contributed to death and mechanism of suffocation, as applicable.⁵ The SDY case registry uses a similar classification system.³ Applying standardised definitions to categorise cases allows researchers and programme planners to differentiate causes and to more reliably monitor SUID and SDY mortality trends and characteristics.

Although many Child Death Review programmes are mandated by state or local jurisdictions to review the circumstances of deaths and make prevention recommendations, programmes often lack resources to conduct population-based surveillance, that is, review of every unexpected sudden infant and child death in a state or jurisdiction. The CDC and NIH cooperative agreements allow for the collection of population-based surveillance data of SUID and SDY, which is then used for continuous quality improvement of death scene investigations, autopsies and prevention strategies. Resulting surveillance data are used to improve knowledge of events and characteristics surrounding SUID and SDY, identify at-risk groups, develop and evaluate prevention and education programmes, promote policy and practice changes for investigation and autopsy and inform prevention activities that can potentially save lives. The CDC and NIH registries also serve as a potential source of cases for case-control, genetic and other analytical studies.

To date, awardees have entered nearly 6200 SUID and 2700 SDY cases into the SUID and SDY case registries, respectively. Mirroring what is reported with US death certificate surveillance, infants in the SUID case registry comprise a higher than expected proportion of

black and American Indian and Alaskan Native infants. In addition, most infants are 4 months of age at death with a slight male predominance. Comparing SDY case registry data with death certificate surveillance is more challenging and cannot be done reliably.³ As expected, the CDC and NIH registries data support evidence that SDY is more common among infants (~80% of SDY cases are infants) and show most infant deaths (99%) occur in unsafe sleep environments.

States and local jurisdictions have made policy and practice changes informed by the SUID case registry data, including implementing child care licensing laws that require adherence to safe sleep recommendations, instituting safe sleep training curricula for child welfare professionals, requiring parent safe sleep education at birthing hospitals, creating an online dashboard allowing for local-level analysis of SUID data and systematically alerting healthcare providers when a patient has died of SUID and reminding providers about the importance of safe sleep education for caregivers. Additionally, awardees have implemented important improvements to death investigations. For example, two states issued statewide mandates for the use of CDC's Sudden Unexplained Infant Death Investigation Reporting Form, a template CDC provides as a tool in an effort to improve and standardise investigations.

The CDC and NIH registries have resulted in more complete and comprehensive surveillance data to study circumstances and characteristics of SUID and SDY than data available from death certificates alone. Because SUID is often unwitnessed, thorough investigations and doll re-enactments are critical to understanding the sequence of events leading to death, and understanding where and how the infant was found. In the United States, more medicolegal offices are using standardised scene investigation reports and autopsy protocols, but there exists opportunities for improvement. Many states have laws requiring thorough case investigations for sudden and unexpected deaths, but the comprehensiveness of these investigations vary by jurisdiction due to differences in training, resources and level of experience. The extent to which laws and mandates that facilitate investigations and autopsies in England and how often they are practised and enforced will be important for the English registry to examine. The US CDC and NIH look forward to partnering with and learning from data captured in England's and other national sudden death registries.

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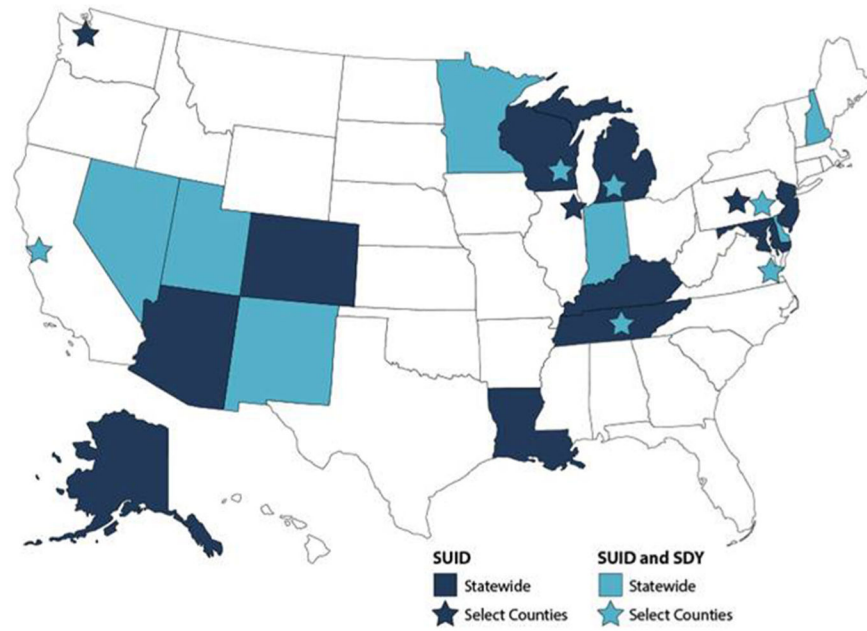


Figure 1.

Centers for Disease Control and Prevention and National Institutes of Health sudden unexpected infant death (SUID) and sudden death in the young (SDY) case registries participants, USA, April 2019. SUID (dark blue) participating states and jurisdictions include Alaska; Arizona; Colorado; Cook County, Illinois; Kentucky, Louisiana, Maryland, Michigan, select counties in Pennsylvania; Tennessee; Pierce County, Washington and Wisconsin. SUID and SDY (light blue) participating states and jurisdictions include San Francisco County, California; Delaware; Indiana; select counties in Michigan; Minnesota; Nevada; New Hampshire; New Jersey, New Mexico; Philadelphia County, Pennsylvania; select counties in Tennessee, Tidewater Region, Virginia; Utah and select counties in Wisconsin. Source: <https://www.cdc.gov/sids/case-registry.htm>.